



**WESTERN SYDNEY**  
UNIVERSITY



Nursing and Midwifery



REPORT OF THE RESEARCH PROJECT: A NATIONAL SURVEY OF

# **AUSTRALIAN NURSES WHO WORK WITH PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITY**

FOR: PROFESSIONAL ASSOCIATION OF NURSES IN  
DEVELOPMENTAL DISABILITY, AUSTRALIA (PANDDA) INC.  
SEPTEMBER 2019

**pandda**  
Professional Association of Nurses in  
Developmental Disability Australia Inc

#### THIS REPORT HAS BEEN PREPARED BY:

**Associate Professor Nathan J Wilson**, School of Nursing and Midwifery, Western Sydney University

**Dr Peter Lewis**, School of Nursing and Midwifery, Western Sydney University

**Professor Lisa Whitehead**, School of Nursing and Midwifery, Edith Cowan University

**Ms Virginia Howie**, School of Nursing, Midwifery and Social Sciences, Central Queensland University

**Dr James Collison**, School of Social Sciences and Psychology, Western Sydney University

**Ms Sarah Feighan**, School of Nursing and Midwifery, Western Sydney University

**Dr Michele Wiese**, School of Social Sciences and Psychology, Western Sydney University

**Ms Kate O'Reilly**, School of Nursing and Midwifery, Western Sydney University

**Mr Hayden Jaques**, School of Nursing and Midwifery, Western Sydney University

#### ACKNOWLEDGEMENTS

We acknowledge the PANDDA Executive Committee for entrusting the research team with this research project.

We also thank the nurses who took the time out of their working day to complete the survey.

Finally, we acknowledge the input of Suzanne Robinson and Irene Rogers, from Edith Cowan and Central Queensland Universities respectively, who worked as research assistants on the project.

#### SUGGESTED CITATION

Wilson, N.J., Lewis, P., Whitehead, L., Howie, V., Collison, J., Feighan, S., Wiese, M., O'Reilly, K., & Jaques, H. (2019). A national survey of Australian nurses who work with people with intellectual and developmental disability: Report to the Professional Association of Nurses in Developmental Disability, Australia (PANDDA) Inc. School of Nursing and Midwifery, Western Sydney University, Australia.  
<https://doi.org/10.26183/5d76e6d07efab>

#### DISCLAIMER

The Professional Association of Nurses in Developmental Disability, Australia (PANDDA) Inc. funded this report. The project was conducted by researchers from Western Sydney, Edith Cowan and Central Queensland Universities in 2018-2019. This final report represents the views of the authors and do not necessarily reflect the views of PANDDA. No endorsement by PANDDA should be assumed. Every effort has been made to ensure that the information contained in this report is accurate.

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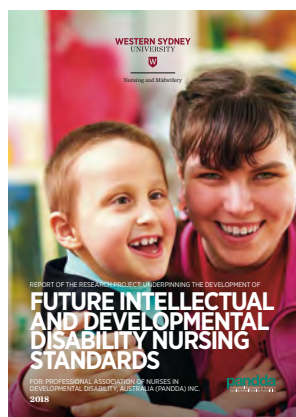
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# PREAMBLE

This report forms Part 2 of a 3-year project led by the Professional Association of Nurses in Developmental Disability Australia (PANDDA) Inc., to redevelop the specialist practice standards for intellectual and developmental disability (IDD) nursing.

Part 1 consisted of literature reviews, interviews with nurses who work with people with IDD, and interviews with nurses who work in acute care settings about their experiences nursing people with IDD. Part 1 has been completed and a final report has been published (Wilson et al., 2018) and can be downloaded here:



Part 2, which constitutes this report, is a national survey of nurses whose primary role is working directly with people with IDD.

In July, 2018, the research contract for this national survey was signed and fully executed for the research team to undertake this research. The project ran from August, 2018 to June 2019.









# BACKGROUND

Compared to the general population, people with intellectual and developmental disability (IDD) have more health problems, poorer health outcomes and die at a younger age.

Nurses play a vital role in the lives of many people with IDD, in particular those with complex support needs, such as chronic and complex physical or mental health problems. Nurses whose main role is to work with people with IDD do so using an approach that earlier research has described as nurse led, relationship-centred care (Wilson et al, 2019). That is, the nurse not only uses an array of clinical skills, but also in-depth relational skills as well as being a vital part of inter-sectorial collaboration alongside the person with IDD and caregivers, such as family members. What is missing from the Australian context, however, is detailed insight into this nursing workforce, a granular analysis of what these nurses do in their day-to-day work, together enabling a richer insight into the roles and contexts in which they work.

This survey aimed to:

1. provide a national overview of intellectual and developmental disability nursing,
2. describe in detail and with confidence exactly what it is that sets this field of nursing apart from other speciality areas,

3. unpack the diverse range of contexts that intellectual and developmental disability nurses are working within, and
4. accurately describe the size and composition of the intellectual and developmental disability nursing workforce in Australia.

## ETHICAL APPROVAL

The research project received approval from the Western Sydney University Human Research Ethics Committee on the 6th August, 2018 (Approval ID: H12836). There were no adverse or unforeseen events to report.







# METHOD

## THE SURVEY DEVELOPMENT

This survey was conducted using a descriptive survey tool was designed and piloted for its feasibility and appropriateness in 2017. This survey development phase was conducted as part of Mr Hayden Jaques' Bachelor of Nursing (Honours) degree which was supported by a PANDDA honours scholarship. Following completion of piloting, piloted, modifications were made to the survey with some areas added to ensure that the breadth of nurses' roles and practice could be captured.

## THE FINAL SURVEY TOOL

The final survey tool consisted of a series of questions within the following six sections:

1. Personal care (covering physical health care, adaptive behaviour, managing problem behaviour, supporting mental illness, supporting spirituality, identity and body image, nursing assessment and interventions, and inter-agency collaborations)
2. Profile of people with IDD cared for
3. Professional contributions
4. Demographic data
5. Professional practice
6. Nursing research.

The questions were loaded onto an online survey platform for completion by interested nurses.

## PARTICIPANTS

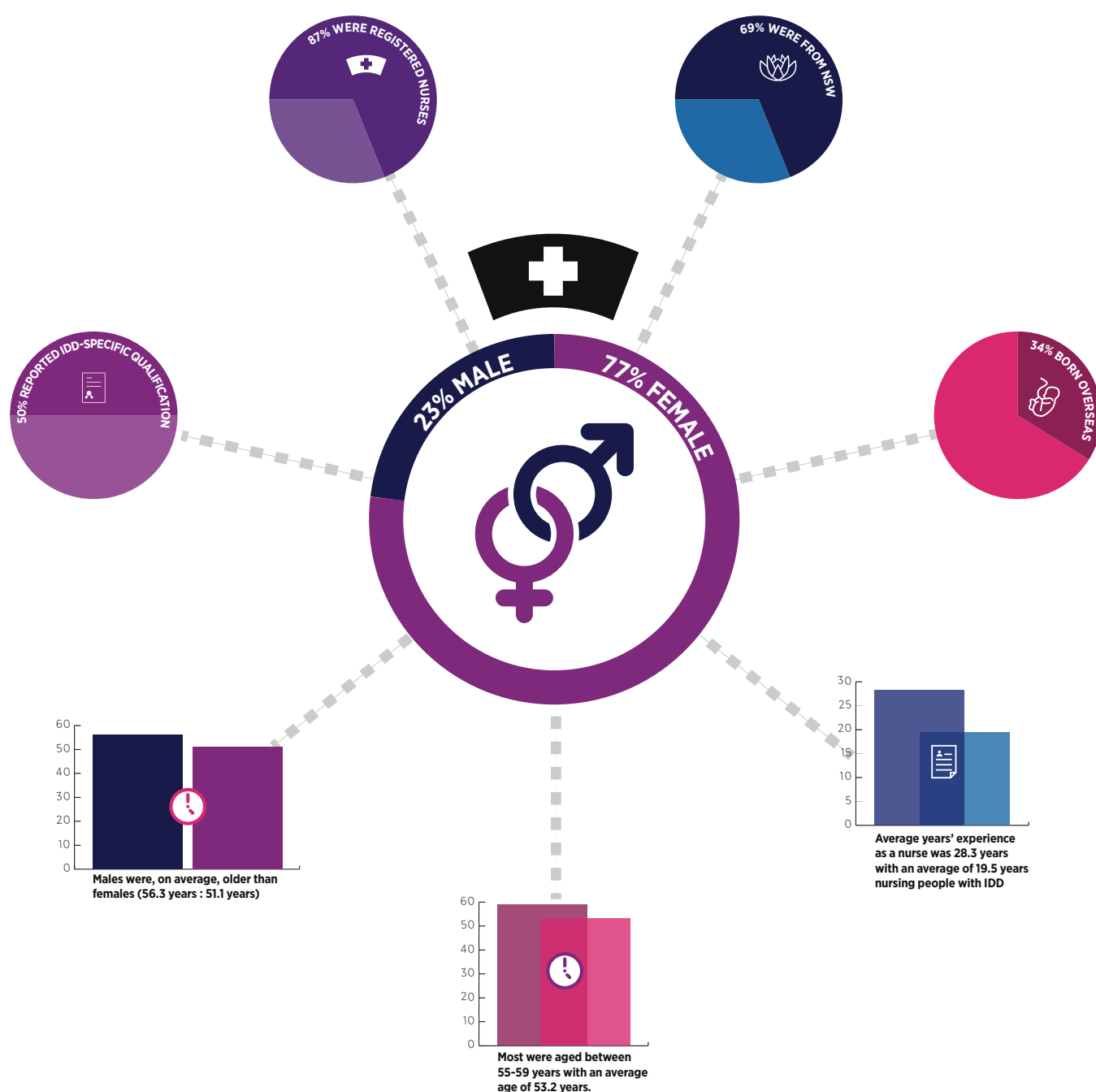
There is no national database of nurses who work primarily with people with IDD. Therefore recruitment was conducted using the publically available list of National Disability Insurance Scheme (NDIS) service providers.

As there were 37 different service categories (as at August, 2018), comprising 70,646 providers, we first reduced this list to those service providers that were potentially related to nursing. For example, we deleted services that were based on transport and the making of orthoses as these are non-nursing areas of service provision. We then deleted services that were allied health specific, such as for psychologists or exercise physiologists, as these are non-nursing roles. Once this process was completed and duplicate service provider entries were also deleted, the final list of registered service providers contacted was 4741. Each of these services was either phoned directly by a member of the research team and/or were emailed a copy of the survey flyer. The primary purpose of this direct contact was to first clarify if the service employed any nurses and, if so, to then invite them to complete the survey.



# RESULTS

## DEMOGRAPHIC PROFILE OF THE WORKFORCE

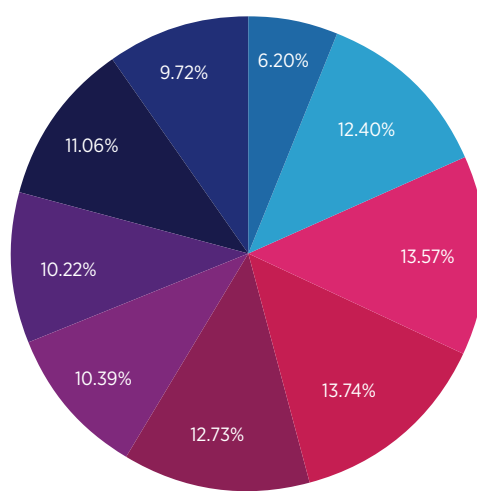


## PROFILE OF PEOPLE WITH IDD SUPPORTED

Most nurses worked in group home settings with adults, with only a few working with children and elderly people with IDD. The majority of nurses worked with male and female clients with IDD, although 27% worked only with males with IDD and 8% worked only with females with IDD.

## NURSING ROLES

- First rated role focus: direct assessment and care of people with IDD
- Second rated role focus: supervision of support workers
- Third rated role focus: education of others



Physical health care frequency

- Genitourinary
- Endocrine
- Cardiovascular
- Integumentary
- Musculoskeletal
- Gastrointestinal
- Neurological
- Respiratory
- Sexual

## NURSING PRACTICE

### 1. Physical health care,

Respondents provided physical health care support across all body-systems, however the gastrointestinal, neurological, musculoskeletal and respiratory systems were the most commonly reported body systems supported

### 2. Adaptive behaviour

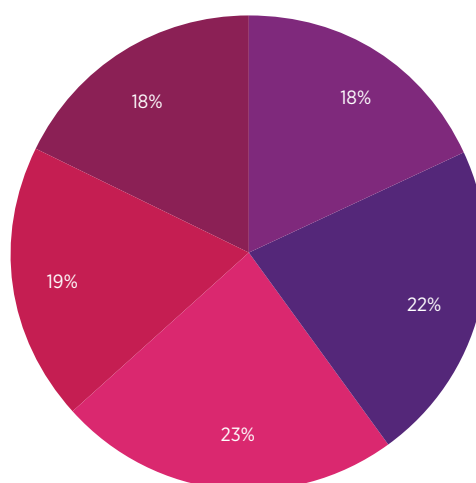
Nurses offered reasonably equivalent support for adaptive behaviour across all domains

### 3. Managing maladaptive behaviours,

Nurses also offered fairly equivalent support across all domains for managing maladaptive behaviour

### 4. Mental health support

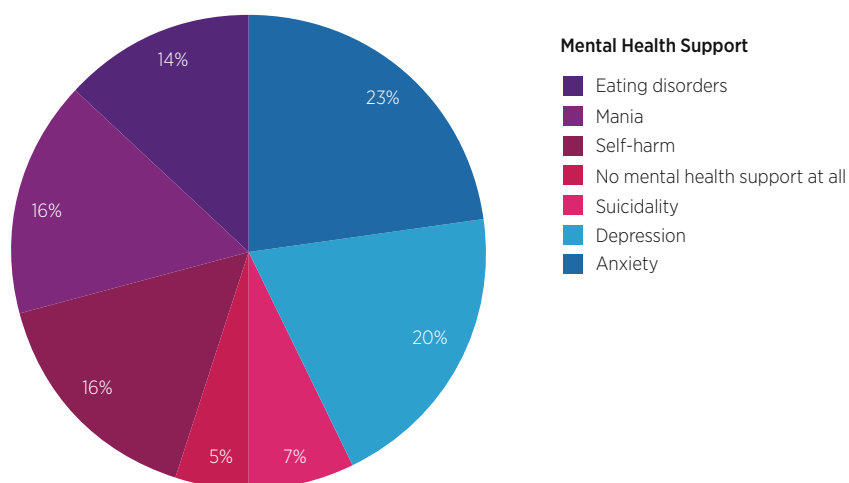
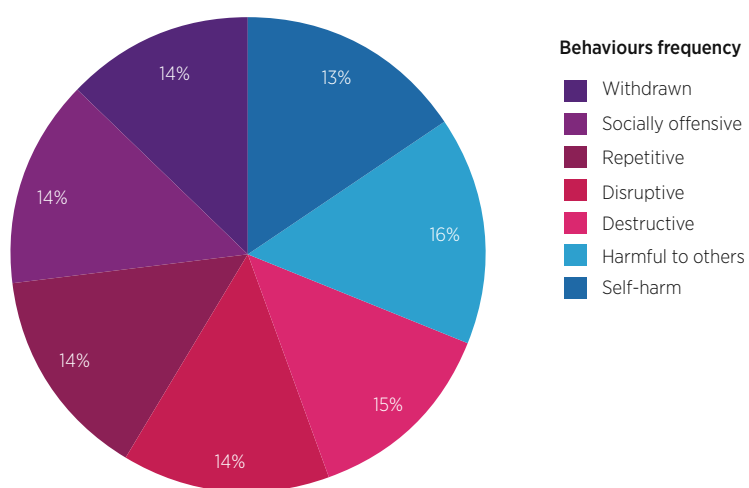
Nurses were significantly more likely to offer support for anxiety and depression than for any other symptoms of mental illness



Adaptive behaviour frequency

- Community living skills
- Personal living skills
- Communication
- Social skills
- Motor Skills





## INTERAGENCY COLLABORATIONS

Nurses interacted frequently with a range of health and social/disability practitioners and systems.

### Health:

The most common health collaborations were with allied health practitioners, medical consultants and GPs.

### Social/disability:

The most common social/disability collaborations were with the NDIS, state-based guardianship services, and other disability service providers.

## RESEARCH PARTICIPATION

Nurses were significantly more likely to read and use research findings than to lead or conduct research with others.



# WHAT DOES ALL THIS MEAN?

## THE NURSES

The current workforce of nurses who work with people with IDD are ageing and the average age of these nurses is proportionally older than the whole Australian nursing workforce. Survey respondents' qualifications varied, suggesting that the IDD-specific education of these nurses is fragmented. This poses many problems for the field of nurses who specialise in caring for people with IDD as well as for people with IDD themselves. That is, there is no obvious and ready replacement for this ageing workforce suggesting that in the near future, people with IDD may be denied access to the specialised skills so necessary to support the range of often complex health conditions common to the experience of IDD.

## NURSING PRACTICE

Overall, nurses who specialise in caring for people with IDD are working across multiple domains. Although focussed on physical health needs, and in particular gastrointestinal and neurological needs, this area of nursing practice consistently covers all adaptive behaviour and maladaptive

behaviour domains as well as some areas of mental health support. Few, if any, other areas of nursing cover such a breadth of practice across the lifespan and within multiple contexts. This makes the area of IDD nursing unique.

## RECOMMENDATIONS

For nurses who work in this field, none of these results are likely to be surprising. Nevertheless, what these data have offered, for the first time in the Australian context, is a description of the workforce as well as evidence outlining the range and depth of nursing practice in this field. Although this report provides a solid summary, the detailed data are to be published in peer reviewed academic journals. These academic sources will give the PANDDA leadership the respected and reliable evidence needed to continue to reconceptualise the role of the nurse who specialises in caring for people with IDD into the future.

The future for Australian nurses who specialise in this field remains at the crossroads with the advent of the NDIS; the key issues facing the field have been discussed in other PANDDA-

funded research (O'Reilly et al., 2018; Wilson, Lewis et al., 2019; Wilson, Wiese et al., 2019). At this moment in time, there are no nurse specific post-graduate pathways for further education in this speciality area, unlike allied health practitioners the role of the nurse is currently sidelined within the NDIS as either a core or capacity-building role as opposed to a direct therapeutic supports role, and the health system has very few IDD-specific nursing roles. Although a very small number of new nursing roles are emerging, for example in NSW Health, there is not a critical mass of nurses in this area as there are in other areas of nursing such as aged care, acute contexts and mental health. Reversing this trend will require leadership from the PANDDA executive as well as from individual nurses to conduct the necessary political advocacy to ensure that people with IDD into the future are not denied the specialised skills that nurses offer.





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